

Quality of life: a deconstruction for clinicians

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Quality of life has been an issue in medical research for more than twenty years¹, and many authorities now regard it as a key measurement in clinical trials^{2,3}. Yet the concept remains controversial. In the clinical world, scepticism is exemplified by a comment by Wulff in the *JRSM*:

‘Scientists may use rating scales and visual analogue scales to measure pain, and they may even invent scoring systems quantifying types of handicaps; but when they talk about measuring quality of life they have gone too far’⁴.

This statement reflects a two-world model of medicine and of human experience in which objective facts are clearly distinguished from subjective values^{4,5}. It can be seen as a reaction to the World Health Organization’s concept of health and of quality of life that invites us to mix facts and values non-systematically:

‘Quality of life is defined as an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment’⁶.

THREE-COMPONENT OUTCOME MODEL

Although we do not share Wulff’s scepticism we also reject the romantic/holistic WHO definition. Instead we propose a three-component outcome model that should be both empirically testable and clinically relevant. Clearly, a patient can only be understood when both ‘worlds’ are assessed. Figure 1 represents a man with colorectal cancer. Looking at the left side of his face we capture his health status in terms of mechanistic outcomes of the kind usually assessed in clinical practice and in research⁷. In assessing these attributes we understand half of his fate. The other

half is composed of psychosocial (hermeneutic) constructs that are assessed from patients’ self-reports. But only when the two halves are put together, and through information exchange the patient and the doctor agree on the most important endpoint of treatment⁸, is the outcome likely to be satisfactory in the patient’s terms.

Our approach to quality of life is based on the principles of experimental social psychology. This relatively new life science proceeds by hypothesis testing. As West and Wicklund⁸ put it, ‘Theories will ultimately be evaluated on their ability to account for the results of existing research, to suggest ideas that can be tested in future research, and to predict correctly outcome of research’⁹.

THE CORRELATES OF QUALITY OF LIFE

With this notion in mind we have conducted a series of studies to aid our understanding of patients’ responses to questionnaires. As a standard instrument we used the EORTC-C30 quality of life questionnaire, which was developed under the auspices of the European Organisation for Research on Treatment of Cancer (EORTC), has been translated into more than twenty languages and is now widely used in international clinical studies¹⁰. The questionnaire covers physical functioning, role functioning, emotional, social and cognitive functioning and various specific somatic symptoms and provides an overall evaluation of the present condition (global quality of life). Briefly, what we learned was as follows.

Symptom distress

Overall, somatic symptom distress was highly correlated with the psychological variables negative affect ($r=0.70$ to $r=0.75$), experienced social stigma ($r=0.51$), social desirability ($r=-0.50$) and positive thinking ($r=0.40$ or $r=-0.40$, depending on whether positive affect or compensatory self-related positive thinking was dominant)^{11–13}.

These psychological variables deserve explanation. *Negative affect* (NA) is defined as a summary category of unpleasant emotional states such as anxiety, restlessness, depression or low self-esteem. Individuals scoring high on NA scales have the propensity to experience such unfavourable emotions. This variable is considered of central importance because of its consistent and strong

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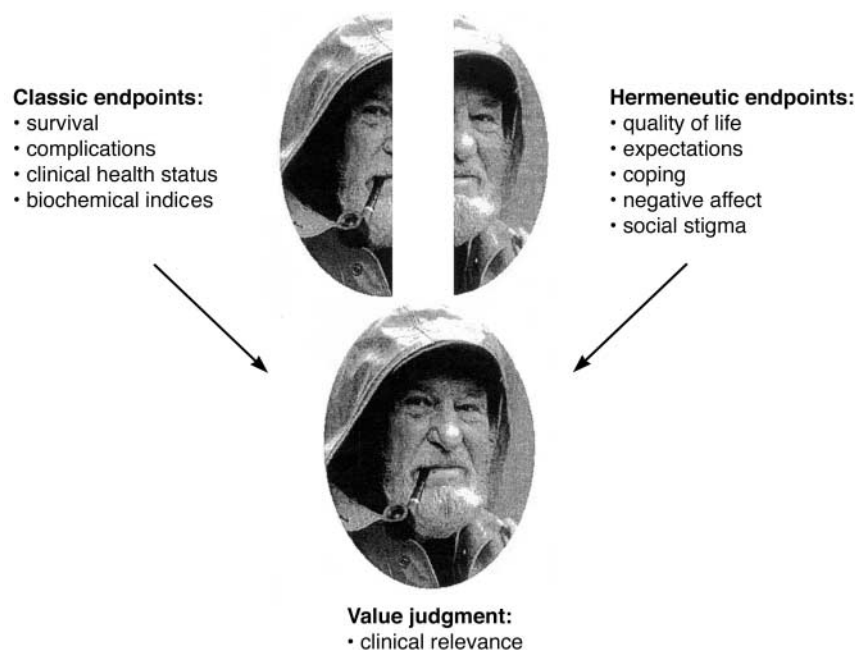


Figure 1 The three component outcome model

relations to health complaints across a variety of studies, in different samples and with different NA measures^{14,15}. Furthermore, there are also national differences in the level of NA¹⁶. These differences have to be taken into account when cross-cultural variations in standardized quality of life scores are under scrutiny¹⁷. NA is also a component of the EORTC questionnaire (items 21–24). Many users are unaware of this, since the questionnaire-developers chose for unknown reasons to label this set of items ‘emotional functioning’.

Social stigma is an individual’s feeling that others treat him/her as a sick person and no longer as a normal member of society. Experienced social stigma can be measured reliably with a 8-item scale¹¹.

Social desirability is defined as readiness to endorse questionnaire statements that are valued by society. Since health is something highly valued in western society, individuals high in social desirability are expected to report few symptoms and high quality of life. Various measures to assess social desirability have been published¹².

Finally, *self-related thinking* is an individual’s proneness to introspection. Preoccupation with positive aspects of the self has been interpreted as a reaction to failure experiences¹⁸; and, since long illness episodes can be regarded as failure experiences, self-related thinking is relevant to the reporting of health complaints and quality of life¹⁹.

The correlation coefficients reported above characterize the association between somatic symptoms and psychological variables. A comparable pattern of results

was observed when these variables were correlated with global quality of life as the quasi-dependent variable. However, both somatic symptoms and global quality of life were virtually unrelated to objective clinical criteria (tumour growth, findings of imaging techniques, carcinoembryonic antigen, external physicians’ overall judgments)^{11–13}. Clearly, quality of life is a domain outside the biochemical/molecular paradigm.

Expectations

Patients and their doctors were asked for their expectations regarding radiotherapy^{20,21}. Both gave their responses before the start of therapy, and it turned out that patients showed a much richer spectrum of expectations than doctors, who focused on pain relief and tumour size reduction. The most dramatic difference was in expectations of cure. 58% of the patients expected cure from radiotherapy, whereas from the doctors’ standpoint this was a realistic expectation in only 7%. In fact, most patients were receiving palliative therapy for advanced cancer. Although the patients were carefully informed, many of them expected to regain their health. In the published work, psychological processes of this sort are labelled ‘positive illusions’²² and ‘denial’²³. A remarkable observation was that those who expected healing had a significantly better quality of life (or those who expected only pain relief had a significantly worse quality of life)²¹. For clinical purposes, we need to know the individual patient’s expectations.

Priorities

Therapy priorities have been investigated in relation to cholecystectomy²⁴. When patients were asked in a qualitative analysis which endpoints they ranked most important for outcome we were surprised by some of the answers. A rapid return to physical fitness—becoming the same as before the disease—was sometimes rated higher than death and more important than pain, hospital stay and cosmesis. Yet in the more than sixty studies comparing laparoscopic with conventional cholecystectomy, return to physical fitness has never been the primary endpoint. Though otherwise well designed, these studies seem to have assessed outcomes that were of more interest to doctors than to patients.

CAUSALITY

When we look at studies of the kind cited above, an obvious question concerns the direction of causation. Do the psychological variables affect somatic symptoms and quality of life, or does quality of life affect the psychological variables? Since we found a large number of variables related to quality of life, we think it futile to seek unidirectional cause-and-effect relations. We prefer to characterize the 'influence variables' as either sufficient determinants or contributory determinants²⁵. This standpoint is backed by experimental studies. With regard to negative affect, bad mood can cause bodily symptoms^{19,26,27}, but under certain conditions the reverse can also be true²⁸. Similarly incompetence can lead to self-related thinking^{29–31}, but individuals are perceived as competent by outside observers when they use self-related terms in describing an activity³². Many phenomena investigated in social psychology have bidirectional, dynamic, causal relationships³³.

The philosophy of science offers numerous definitions and concepts of causality, and that of Collingwood is particularly appropriate for the present discussion³⁵. According to Collingwood, a cause is something that can be *altered* in order to instigate a desired change in a given environment. From this perspective, if a specific precondition (e.g. gene defect) of cancer has been detected that can *not* be altered by humans, this is not regarded as a cause. The quest for a cause continues until cancer can be successfully treated. Quality of life is an abstract term and there is no accepted way to enhance the quality as such. However, more concrete aspects such as expectations, negative affect, social stigma or patient preferences can be foci for intervention. Patients' expectations should be modifiable through careful information^{36,37}, their negative affect through psychotherapeutic interventions^{38–40}, and social stigmatization by influencing the family environment¹¹ or bringing patients' preferences into harmony with

medical decision-making⁴¹. These settings also would allow for testing of specific unidirectional hypotheses within randomized controlled therapeutic trials. Furthermore, the correlational studies enhance our understanding of patients' responses to standard quality-of-life questionnaires. Such questionnaires produce results that are hard to interpret without additional information. 'Naked' quality-of-life-scores yield no real understanding of the patient's personal experiences. One has to know the network of variables in which the assessments are embedded.

AN EMPIRICAL DEFINITION OF QUALITY OF LIFE

From the above considerations we arrive at an experimentally and empirically based definition of quality of life that differs from the philosophical WHO definition (Box 1). This conception is now described in more detail.

Box 1 Our concept of quality of life

Assessed in disease—the critical model
Self-perception and self-report in 3 domains: somatic, psychological, social
Includes health-related and therapy-related expectations and coping
Is influenced by psychosocial variables such as negative affect
Is part of a three-component outcome model including mechanistic endpoints, hermeneutic endpoints and a qualitative analysis of clinical relevance

Health-related or disease related?

When assessed in patients, quality of life is *not* related to health (as is commonly argued in textbooks and journals)⁴², but is rather related to disease, and in particular to a specific disease⁶. The critical model of disease is defined by a combination of the biological model of disease and the psychosocial model in which the patient suffers and seeks help from the doctor^{7,43}. This viewpoint is very different from the 'having fun' stereotype of a good quality of life. Current quality of life questionnaires have been developed for and validated with ill people. The psychological predicament and consequently the concept of quality of life of ill people may differ from that of 'healthy' or 'normal' people. Specifically, patients have something socially and personally undesirable, namely an illness; they want to get rid of this condition, to get from one state to another; patients' physiological abnormal state (with raised levels of cytokines etc.) may affect the psychological state and thus questionnaire responses; notions such as palliation are outside everyday human experience, so special assessment instruments are necessary^{44,45}.

Self-reported or physician-assessed?

'Self-reported' means that quality of life is not assessed by the doctor but via a questionnaire used under the patient's control. It does not simply consist of a statement of symptoms such as pain yes or no, but also provides an evaluation such as severe or intolerable. Three groups of dimensions (domains) are included—somatic symptoms such as pain; psychological components including emotion, cognition and general consciousness; and social components such as family, work and sexual satisfaction.

Judgments of overall wellbeing or coping

Several questionnaires (EORTC, SF36) ask for a person's overall judgment of quality of life.^{46,47} This judgment must not be confused with the aggregation of a summary score across different quality-of-life components, as preferred by other questionnaire designers^{48,49}. At individual patient level, clinical experience teaches that some patients rate their overall quality of life as quite good when they are clearly very ill. We give an example later. In aggregate patient samples, regression analyses show that objective health variables and self-reported health variables do not fully explain the variance of global quality of life^{11,12}. A famous example is the work of Brickman *et al.* showing that, after an adaptation period of one year, paraplegic accident victims and lottery winners reported practically the same level of overall wellbeing⁵⁰—a phenomenon known as the wellbeing paradox⁵¹. Seemingly, an overall judgment of quality of life includes a component of *coping*⁵².

QUALITY OF LIFE PROFILE AS A TOOL FOR INDIVIDUAL PATIENT CARE

How can quality-of-life measurement contribute to care of the individual patient? What changes or differences are clinically important? Is a value of 48 on a 0–100 scale good or bad quality of life; is a change from 48 to 61 an important improvement? Despite research from various directions^{53–56}, there is so far no consensus on these issues. Here we propose an approach based on our outcome concept and embedded in clinical reality. Since doctors like to work with visual material^{58–60} we present quality-of-life profiles graphically⁶¹. For this purpose the individual answers to the EORTC questionnaire items (50–60 altogether; 30 items core questionnaire; 20–30 additional symptom/disease specific module) have to be transformed into quality-of-life scores. Individual items of the EORTC questionnaire that correspond to one content dimension are grouped, summed and then linearly transformed into a 0–100 point scale in which 0 represents the worst outcome. About ten scores are arranged vertically and individual patient data can be displayed on a chart like other information in the medical record.

For two reasons, a score value of 50 can be regarded as the threshold level for intervention. First, the EORTC QL questionnaire items tap into patients' degree of impairment and answers can be given on response scales of 1–4 (1=not at all, 4=very much so). Responses can be easily dichotomized with 3 and 4 the 'bad' side and 1 and 2 the 'good' side⁶². Second, according to psychological theories on adaptation level and social comparison, persons generally try to perform slightly better than average⁶³. Clearly, therefore, values under the average (50) are undesirable; the goal of therapy is to bring patients over 50. Note that, at least for global quality of life or overall happiness, a value of 100 is not necessarily desirable all the time. Highest levels of happiness also involve intense physiological arousal which may be burdensome and distracting if it lasts too long. Therefore, 'good' or desirable overall quality of life is usually between 60 and 80 points on a 0–100 scale⁵¹.

Although a threshold level of 50 seems reasonable, it is clearly not an immutable law. Clinical research may tell us that a focus on extreme levels is more useful. Furthermore, the threshold must also take into account cultural and individual differences^{16,64}. In medicine, the norm can change, as illustrated recently in hypertension⁶⁵. Until this issue of the threshold is settled by research, we shall use the 50-point score as a starting point.

Two patients

Let us illustrate how our concept of outcome and quality of life relates to individual patients and their treatment. Two patients, A and B, were enrolled in a randomized study of G-CSF prophylaxis in patients undergoing operation for colorectal cancer⁶⁶. Quality of life was assessed pre-operatively, at discharge and, at months two and six postoperatively. The last assessment included an in-depth standardized interview in which the patient was invited to report on the most important aspects of the illness episode.

In terms of *objective health status* these two patients were very different (Box 2). Patient A had a T1 tumour of the rectum, giving him a 5-year survival chance of 90%. His postoperative complications included focal anastomosis leakage and neurologically disturbed micturition until six months postoperatively. Patient B had a T4 tumour (5-year survival chance 50%). Furthermore, postoperative complications included not only disturbed micturition but also a cerebral infarction. Let us now turn to *global quality of life* (Figure 2). For the entire period patient B, more severely ill, displayed higher global quality of life than patient A. This is particularly evident in the area under the curve (Figure 3). These results are striking because they do not follow the lead of the individual score points. Interestingly, patient A displays no <50 values. In contrast patient B, despite numerous lower scores, particularly in role and

Box 2 Characteristics of patients A and B

	A	B
Age	58	67
Sex	M	M
ASA	3	3
Diagnosis	Rectal carcinoma	Recurrent rectal carcinoma
Operation	Low anterior resection, ileostomy	Low anterior rectum resection, bladder resection, ileostomy
Tumour	pT1 pN0 pM0	pT4 pN0 pMx
Hospital stay	25 days	39 days
Intensive-care requirement	2 days	6 days
	Pyrexia day 5, localized anastomotic leakage, disturbed micturition for >6 months	Stroke on day 4; disturbed micturition 2 months

cognitive functioning, has an acceptable overall quality of life throughout the follow-up.

As a next step *background information* (basic psychological variables, medical record, interview with patient) has to be inspected. Patient A expected healing from therapy; that is a positive sign and should have helped in recovery. The interview at six months revealed why his recovery had been relatively slow. He explained that the stoma had been the most important therapy-related problem. Although it functioned, it was psychologically a big shock (it was removed four months postoperatively). When asked about his best experience, he mentioned his leisure time, although he had too much. When asked what was the most important event, he named nothing specific except that he was still alive. Furthermore, he said that there were no important changes in his life. It is very striking that this patient never mentioned his family or friends. All in all, he gave the impression of a rather empty life.

Patient B also had expectations of cure, and at the onset of therapy had a lower degree of negative affect than patient A. This may partly explain why his overall quality of life was better despite postoperative troubles including a stroke. At the six-months interview he said that his worst experience had been the diagnosis and his best had been getting back to his family. His medical condition was preventing him from fulfilling previous social commitments, but his family and friends were supportive and he was getting lots of visits. Thus, unlike patient A, this patient had a very active social and family life.

Consequences for individual care and regional health care

These examples show that quality-of-life profiles can be read like an electrocardiogram or any other functional test. The profile does not replace the conversation between

doctor and patient. On the contrary it may stimulate useful discussion—as in patient A, where the interview disclosed reasons for his poor recovery. We would advise such a patient to take up social activities or a hobby that make better use of his leisure time. Patient B might benefit from physical therapy and advanced stoma therapy; he has to be persuaded that the stoma does not preclude social activities.

Our experience with quality-of-life assessment in patients is promising. Patients accept this endpoint and are happy to be asked about matters that ‘really count’ for them. Doctors, too, are beginning to accept quality of life as an endpoint and a diagnostic tool. In an implementation study, quality-of-life profiles have been routinely sent to the doctors in charge of follow-up treatment of cancer patients. Through various implementation strategies (academic detailing, outreach visits, continuing medical education) doctors have been taught that 50 points is the level for intervention and lower values may indicate a clinically relevant deficit. All the doctors found the profile easy to understand, and more than half said it led to more information and better communication⁶⁷.

On the basis of our experience with quality-of-life assessment, we restructured follow-up care for cancer patients in our region^{67,68}. A list of treatment options that appear beneficial for improving quality of life and that are available in the region has been compiled⁶⁹. The major domains of intervention doctors can choose from and that can be evaluated by follow-up quality of life assessments are:

- Pain relief and therapy
- Physiotherapy
- Psychotherapy
- Improving physical fitness (sports and nutrition)
- Social rehabilitation.

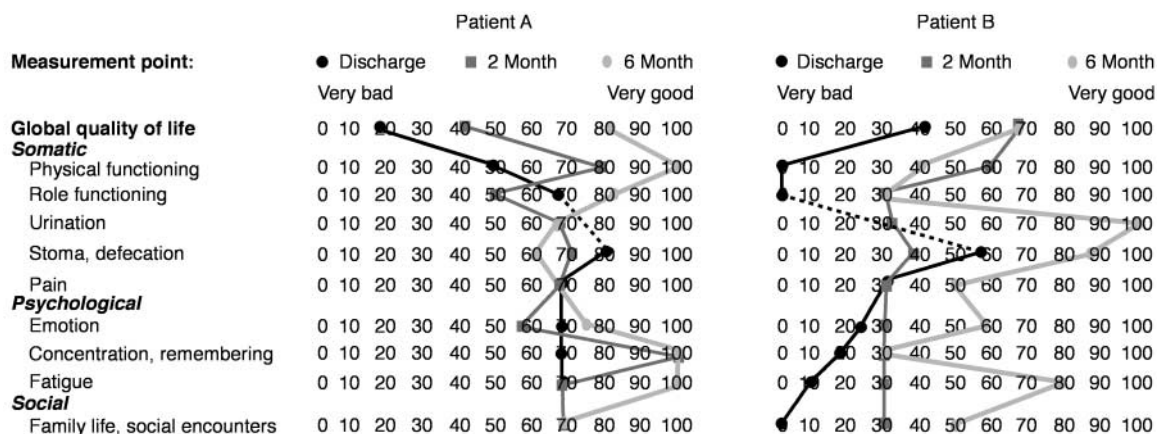


Figure 2 Quality-of-life profiles of two patients

Furthermore, guidelines now include quality of life as an essential endpoint for care^{68,70,71}.

CONCLUSIONS

In this article we have avoided getting caught up in arguments about what is quality of life and whether it can be assessed. Instead we have tried to see how the features assessed under the heading 'quality of life' relate to measurable indices in the clinical arena. Recent advances in research methodology are likely to enhance our understanding of these relations⁷².

Acceptance of the quality-of-life concept within the medical community will depend on its contributions to better understanding of patients and of treatment effects. Thus, we propose a profile format that clinicians readily understand, in which deficits in particular domains are easily recognized. The reasons why a particular deficit exists,

however, is not always evident from the profile. The patient has to explain⁷⁵. In other words, a quality-of-life profile is not a substitute but a starting-point for a patient-doctor interaction. The interaction can be structured and efficient, and the benefit of any action taken can then be assessed by a further profile. There is no contradiction between this empirical approach, and doing something 'humanistic' for the patient.

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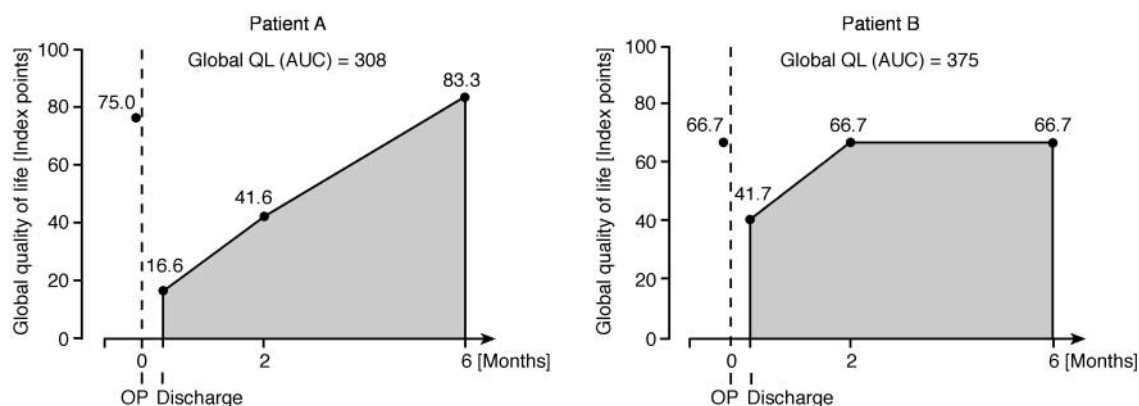


Figure 3 Global quality of life (QL) of patients A and B before and after an operation. AUC=Area under the curve

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